CHAPTER 23

Engaging Communities to Identify Needs and Develop Solutions: Participatory Research Incorporates Community Voice in All Aspects of Health Research Decision-Making

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LEARNING OBJECTIVES

After reading this chapter, you should be able to:

1. Summarize principles of participatory research and distinguish between traditional research and participatory research.
2. Describe and understand the benefits and value, as well as the challenges, of participatory research for community and for the research process.
3. Describe how participatory research underpins knowledge translation.
4. Appreciate who is community, how community is represented, and the ethical implications surrounding community.
5. Provide examples of how participatory research has been incorporated into various research designs (such as randomized control trials).

BACKGROUND

Participatory research (PR) is an approach to research that fosters equity and self-determination through engaging individuals and communities to contribute their knowledge and expertise in shaping scientific inquiry—and so it gives voice to marginalized or underserved populations. PR builds research partnerships *with* communities for the goals of incorporating local expertise to identify community issues and develop the evidence and interventions. This contrasts with top-down research *on* or *about* communities and interventions developed *for* communities by external *experts*, including policy-makers, health officials, health professionals, and researchers. PR is the systematic co-creation of new knowledge by researchers working in equitable partnerships with those affected by the

issue under study, or those who will benefit from it or ultimately act on its results (Green et al. 1995; Israel et al. 1998; Macaulay et al. 1999). Partners can include communities, patients, health care providers, and policy-makers. PR encompasses any research design and is not a methodology but rather an approach to equitable co–decision-making. Thus, PR promotes social justice, self-determination, and knowledge utilization (Cargo and Mercer 2008) by increasing communities' capacity to identify and address their own issues and increasing decision-makers' and service providers' abilities to mobilize resources and improve policies and professional practices (Gaventa and Cornwall 2006; Macaulay et al. 1999; Minkler and Wallerstein 2008).

PR also integrates *knowledge translation* by including appropriate end-user partners in decision-making throughout the research. Partners should be offered full engagement, but they may choose not to be involved in every stage, such as the development of tools or the collection and analysis of data. Significantly, partners should be involved in finalizing the research questions, interpreting results, and disseminating and applying findings (Macaulay et al. 1999; Minkler and Wallerstein 2008; Parry, Salsberg, and Macaulay 2009; Salsberg, Macaulay, and Parry 2014). *Integrated knowledge translation* is the preferred means of co-creating action-oriented knowledge to assure that contextual factors are always central to knowledge production, thus improving relevance and knowledge uptake (Salsberg, Macaulay, and Parry 2014; Straus, Tetroe, and Graham 2009).

PR builds on the existing strengths of individuals and communities. Community members, including those in marginalized or under-served communities, know best how to approach problems, and they have an intimate understanding of their social environments and ways to build on existing resilience (Kirmayer et al. 2011).

It Doesn't Matter Who Asks Whom to Dance

Some researchers are concerned that their project cannot be truly participatory if the question did not originate from their knowledge-user partners. While it is certainly true that if the research question comes from the end-user group, you can guarantee that the group has an interest in the project and the results, this is not the only way to get there. The impetus can just as easily arise from the researcher, and can be successful, as long as it resonates meaningfully with the knowledge users. Sometimes researchers, familiar with the current state of their field, are better situated to identify an issue as needing investigation, and can bring this to the attention of those who may need to know.

CASE STUDY 1—HEALTH PROFESSIONAL INITIATION

A nurse is very concerned that many patients, especially those from various ethnic and Indigenous communities, are not completing their treatment for tuberculosis (TB). She tells her concern to a researcher who suggests partnering with representatives from

these communities. The end result is a research team, including research associates from seven ethnic communities and three Indigenous communities, with goals to identify and understand sociocultural factors and improve practices for prevention and treatment of TB. The team developed guiding foundation principles, and the community partners helped finalize the questions, interview their community members, interpret the results, and disseminate the findings back to their communities. Outcomes included six single-page information sheets in the languages of participating communities, which were also printed in local newspapers and featured on a local radio call-in show; an educational video; and a nurse educator who would visit high-risk communities with new research-based knowledge and community-specific TB prevention strategies. The trained community research associates gained new skills useful for further employment (Gibson et al. 2005).

CASE STUDY 2—RESEARCHER INITIATION

A researcher wishes to conduct a systematic review of *the benefits of using participatory research*. She first assembled a team of co-investigators, including experts in all the areas needed to strengthen the review. The team then imagines the possible end-users of the knowledge they hope to produce and forms a list of possible decision-maker partners, including funding agencies, university ethics review boards, public health agencies, and organizations dedicated to promoting participatory research with both community and academic members. These partners are approached, and one stakeholder from each of these domains agrees to join the project. As partners, they then contribute to refining and finalizing the study design for the grant application and commit themselves to partnering on the research and disseminating and applying results within their organizations (Jagosh et al. 2011).

CASE STUDY 3—COMMUNITY INITIATION

An Indigenous physician in a family medicine resident training program undertakes a chart review in his community hospital and determines that the prevalence of type 2 diabetes among adult members of his community is twice as high as the national population. Beside publishing these results in a mainstream clinical journal, the resident and his supervisor present these results to community members and political leaders who, naturally, find these rates alarming. They are particularly concerned that their children, grandchildren, and the *seventh generation* going forward do not have to bear this same burden, so they ask the family doctors to "*do something about it*." The doctors reply that they are not sure what they could do but would seek advice from research colleagues at the university. This community prompting led to a long-standing community-based participatory research project (see the Kahnawake Schools Diabetes Prevention Project [KSDPP] case study further down in this chapter) (Macaulay et al. 1997).

COMMUNITY

Who represents community? This is an age-old question (Green and Mercer 2001). Classically, communities form community advisory boards (CABs) or committees to partner with researchers. CAB members are frequently those whose lives are affected by the issue under study, community leaders, representatives of community organizations, and interested individuals. Depending on specific goals, CABs may also include health professionals, service managers, and policy-makers (Malus et al. 2011). At the beginning, the important question is, "Who is in a position to use the results to effect change?" If decision-makers are included from the beginning, they will be well placed to trust the results and use their positions to speed knowledge uptake. Guidelines exist for assessing the appropriateness of partnerships and their level of engagement (Mercer et al. 2008).

THE EVIDENCE FOR PR BENEFITS

A systematic review of PR partnerships with high levels of community engagement, co–decision-making, and co-governance (Jagosh et al. 2012) documented multiple benefits. PR generates (1) culturally and logistically appropriate research characteristics for shaping the scope of research, developing and implementing program and research protocols, interpreting data, and disseminating findings; (2) the capacity to recruit community members to advisory boards, for implementation, and as program recipients (intervention enrolment); (3) the capacity of both community and research partners; (4) conflict between partners that, when resolved, leads to positive outcomes for subsequent programming; (5) the accumulation of partnership synergy through repeated successful experiences, thus increasing the quality of outcomes over time; (6) sustained goals beyond initial funding and during funding gaps; and (7) systems change and new unanticipated projects and activity. Interviews with researchers and community members showed that implementing and maintaining trust was a key element, with projects evolving through *ripple effects*, where outcomes of one stage formed the context for the next stage (Jagosh et al. 2015).

PRACTICAL STAGES IN PR

PR may start with a community-identified action need, or a researcher-identified knowledge gap. Whichever its origins, what is important is that all partners agree on the relevance of the issue. While researchers provide methodological know-how, partners provide expert knowledge on context, history, and setting. PR is an exercise in trust building, particularly in cases where partners have been ill-served or harmed by past research. Community members should have opportunities to fully understand the knowledge-creation process, including opportunities for collecting and analyzing data.

Community partners *must* be involved in interpreting the results, as they know best what findings mean within their context (Macaulay et al. 2007), and they must have a full voice in crafting messages both for their peers and the larger academic and practice communities. This strengthens the messaging and mitigates stigmatizing language, which has frequently harmed communities (Katz and Martin 1997).

PR CHALLENGES

What can be challenging for researchers is learning how to work as members of a team, learning how to respect other viewpoints, sharing power and authority, developing positive relationships, understanding different agendas and time frames, developing the flexibility required to accommodate unexpected events, building trust, and finding mutually beneficial solutions (Salsberg, Macaulay, and Parry 2014). Community partners face similar challenges, including the need to understand the importance of research rigour and university time frames. To overcome these barriers, researchers need to develop skills that include active listening, lay communication, nominal group processes, negotiation and conflict resolution, the ability to work in multicultural environments (including multidisciplinary cultures), self-reflection, and the ability to admit one's errors. Most importantly, researchers must develop humility: a willingness to learn from community—to recognize that others have knowledge and experiences that, though very different than their own, will make valuable contributions (Mercer et al. 2008; Salsberg, Macaulay, and Parry 2014).

ETHICAL GUIDELINES

All research requires adherence to mandated bioethical regulations. Beyond individual informed consent, partnership research *additionally* requires obtaining community consent. In Canada, this is outlined in the second edition of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2) (Panel on Research Ethics 2014). In addition, researchers must adhere to setting-specific ethics (see Healey, Chapter 20 in this volume, and the KSDPP case study below).

Important PR ethical considerations include the following: Who represents the community, and do they have a legitimate voice recognized by the community members implicated in the research? Who owns the data and the results? A useful data ownership framework is OCAP® (*ownership*, *control*, *access*, and *possession*), developed by the National Aboriginal Health Organization (NAHO 2007). Also, does your institutional ethical review board allow for prior or parallel community review? TCPS2 requires that in certain circumstances, the ethical review board include community representatives; however, separate prior or parallel review by a community board allows for a stronger community voice and greater community protection.

COMMUNITY-LED RANDOMIZED CONTROL TRIALS

PR has a long heritage of use with small localized groups of people, geographical communities (e.g., Indigenous communities), people sharing a common experience (e.g., people with HIV/AIDS, refugees), and urban ethnic communities. However, PR can be multicentred, national or international in scope, and now includes large-scale community-led randomized control trials (RCTs).

RCTs are often upheld as the gold standard for determining effectiveness and are necessary to generate the evidence to sway policy-makers to allocate resources. Therefore, we should merge the evidence-generating power of RCTs with the community empowerment and action power of PR.

Rebuilding from Resilience was a partnership of 12 Indigenous women's shelters across Canada, and the first Indigenous, completely community-run clustered RCT. This tested the impact and cost implications of evidence-based community-led initiatives to decrease domestic violence (Andersson et al. 2010). For the women's shelters, randomization was a fair way of working out whose turn was next to receive the available resources. At a design meeting, each shelter director drew a number out of a hat, indicating whether their shelter would join the first wave or the second wave. The comparison between the first wave and a second wave provided the "control" comparison—that is, the second-wave baseline provided an unexposed contrast for the follow-up study of the first wave after two years of interventions.

In another community-led trial conducted in Mexico and Nicaragua, communities were engaged to discuss evidence on dengue in their region, local volunteers received training, and communities selected and implemented their own dengue prevention strategies (Andersson et al. 2015). Both trials were examples of how communities reduced gender violence and dengue infections; they were not about externally developed, silver-bullet behaviour-change interventions (Iwama et al. 2009).

CASE STUDY: THE KAHNAWAKE SCHOOLS DIABETES PREVENTION PROJECT

The Kahnawake Schools Diabetes Prevention Project (KSDPP) is a long-established PR partnership between the Kanien'kehá:ka (Mohawk) community of Kahnawà:ke (Quebec) and university-based researchers. For two decades, KSDPP has undertaken numerous PR projects focusing on intervention and policy programming for the primary prevention of type 2 diabetes (see http://www.ksdpp.org and http://pram.mcgill.ca/ksdpp_pubs.php for all KSDPP scientific publications). All research is overseen by the community advisory board (CAB) and follows the *KSDPP Code of Research Ethics* (KSDPP 2007; Macaulay et al. 1998)—jointly developed principles emphasizing community self-determination and Kanien'kehá:ka world view. Thus, KSDPP assures that

all research addresses community-identified needs and combines scientific rigour with Kanien'kehá:ka traditional values and decision-making. This exemplifies *two-eyed seeing* (Hatcher et al. 2009; Iwama et al. 2009), incorporating both Western and Indigenous knowledge frameworks.

Social-Relational Understandings of Health and Well-Being from an Indigenous Perspective

In response to a discussion regarding increasing community programming for diabetes prevention, a project was established to examine how well-being was understood within Kahnawà:ke (Hovey, Delormier, and McComber 2014). The researchers employed philosophical hermeneutics (Davey 2006; Gadamer 1989, 1996; Hovey 2014) with Haudenosaunee (Iroquois) world view and ways of knowing to value Kanien'kehá:ka concepts of holistic well-being, while respecting the unique social and historical context of Kahnawà:ke to achieve a decolonized research approach. This approach structured the collection, analysis, and interpretation of interviews conducted with key community stakeholders. Findings revealed that the *social* conditions created by external Western influences on culture, language, and epistemologies are strongly connected to the *relational* conditions that continue to influence the health and well-being of individuals, families, and the community—a sentiment echoed in other Indigenous communities (see Healey, Chapter 20 in this volume). In Kahnawà:ke, well-being was closely related to being *Onkwehón:we* ("real human beings who live with spirit"), to the roles and responsibilities of families as nurturers of health-promoting relationships, and to processes promoting the healing of multi-generational traumas rooted in colonization. Developing a shared understanding of what is required to effectively prevent type 2 diabetes while simultaneously fostering the sense of being Onkwehón:we is a new approach to health promotion within Kahnawà:ke. This may have relevance in other Indigenous communities with health issues rooted in similar historical and social-relational conditions.

Influencing Policy

KSDPP and two community elementary schools partnered to develop and implement a School Wellness Policy to promote healthy nutrition and physical activity (Hogan et al. 2014). This policy includes the community-identified need to develop school active transportation (AT) to increase physical activity through walking or biking to school (Active Healthy Kids Canada 2014; Buliung et al. 2011). With KSDPP and school support, a doctoral student, with expertise in school AT, initiated a School Travel Planning (STP) project (Macridis 2015; Macridis et al. 2016; Salsberg et al. 2017). The student recruited an STP committee comprising teachers, parents, school administrators, transportation management, a community protection representative, and KSDPP intervention staff, who met monthly from January 2013 to August 2014.

Engagement and Knowledge Co-creation

Following the *KSDPP Code of Research Ethics* (KSDPP 2007), the research was jointly developed, and data were jointly collected, analyzed, and interpreted, which contributed to a context-specific and evidence-informed STP Action Plan for the elementary schools. The first eight months were spent building trust, designing the research, and planning data collection activities, time lines, and terms of reference. All committee members participated in one or more data collection activities based on discussions of Active and Safe Routes to School (Green Communities Canada 2012), including on-site traffic observations, walkability assessments, and in-class mapping by elementary school children (Macridis 2015; Macridis et al. 2016; Salsberg et al. 2017). Involvement in data collection and providing feedback on analysis afforded members first-hand research experience.

Integrating Knowledge Translation Activities

Committee members combined their expertise with baseline findings and translated these into actions for each school. General goals included reducing traffic congestion, increasing

Insights from Community Stakeholders

The participatory nature of the STP project allowed for community stakeholders to share and learn about their unique experiences and perspectives, both personally and professionally. Before the project began, a community stakeholder stated, "there [were] a few things we knew about ahead of time. First and foremost, it was the safety aspect of it. Ya know, parents are extremely over protective." Through involvement in the STP project, members were able to validate preconceptions and learn about newer issues and ideas: "When we get the information about rolling stops, the amount of kids that walk to school, where they live in comparison to their school, like in terms of the whole logistical map and all. I think it's extremely informative" (community stakeholder). Upon further reflection, a community stakeholder stated,

> Well, overall it's been a good experience and I like to share my input and hear others' input in this.... Ideas are sometimes things I haven't thought of. Sometimes a simple sentence from somebody and my wheels start to turn.... When you're in a group setting, and listening to other people elaborate on something, it's ... you're hearing different perspectives. It's something we need more of, ya know? Like in communications, so it's umm ... I think it's been good.

Source: Macridis (2015).

traffic-pedestrian safety, and increasing the number of children using AT. Over the entire STP project, the PhD student fostered community ownership over the research and AT program (Salsberg, Macridis, et al. 2015; Salsberg, Parry, et al. 2015; Macridis et al. 2016; Salsberg et al. 2017), including encouraging an open research environment, building trust, contributing to other community events outside of the immediate project, building research capacity, planning project goals and products relevant for committee members—both within the STP project and their day jobs—and reminding committee members that this was *their* project to run after the student departed (Salsberg, Macridis, et al. 2015). These actions successfully fostered project ownership among key committee members (Salsberg, Parry, et al. 2015; Salsberg, Macridis et al. 2015; Macridis et al. 2016; Salsberg et al. 2017). Community ownership is important for long-term sustained program maintenance and impact, particularly when an outside researcher initiates the project (Salsberg, Macaulay, and Parry 2014). The STP project contributed evidence to promote active living. Moreover, examining community participation in this project provided insights on building community ownership and self-determination.

CONCLUSION

Participatory research meaningfully engages community stakeholders in partnerships to create and apply new knowledge to address identified needs. By definition, PR is action-oriented, and such approaches promote social justice and community self-determination. By fostering environments where communities identify their needs and develop their own solutions, PR redresses a history of often ill-fitting solutions imposed by mostly well-meaning outside research. Today, PR philosophy and engagement have been scaled up to generate high-value evidence serving local needs while being generalizable to other settings. PR creates knowledge and interventions that come from pragmatic, real-world contexts, and are thus deemed more appropriate and easily translatable in community settings. PR approaches are highly recommended for all community-based, action-oriented evidence creation, notably for under-served populations.

CRITICAL THINKING QUESTIONS

1. **Is it possible for a community to "research itself"?**
2. **What additional ethical issues, beyond those in all research, must be considered in participatory research?**
3. **How can participatory research make evidence more relevant and *usable*?**
4. **How can mutual trust act as a key mechanism in change?**

RECOMMENDED READING

Minkler, M., and N. Wallerstein., eds. 2011. *Community-Based Participatory Research for Health: From Process to Outcomes*. Hoboken, NJ: John Wiley & Sons.

This classic community-based participatory research (CBPR) textbook, now in its third edition, provides the perfect primer for those new to participatory research; it also serves as a rich source of insight for seasoned practitioners. The text provides history, background, and philosophy of CBPR alongside exemplar chapters from various application contexts.

Jagosh, J., A. C. Macaulay, P. Pluye, J. Salsberg, P. L. Bush, J. Henderson, E. Sirett, et al. 2012. "Uncovering the Benefits of Participatory Research: Implications of a Realist Review for Health Research and Practice." *Milbank Quarterly* 90 (2): 311–46.

This systematic review of CBPR takes a critical realist approach to unpacking the mechanisms that underlie effective and impactful engaged research. It was the first study to identify the added benefits of long-term partnerships, as well as the value of *productive conflict* within partnerships.

Denzin, N. K., Y. S. Lincoln, and L. T. Smith, eds. 2008. *Handbook of Critical and Indigenous Methodologies*. Thousand Oaks, CA: Sage.

This textbook serves as the perfect reader for critically approaching the methodological and epistemological divide from the perspective of those whose world views have historically been drowned out by the Western gaze. It contains both theoretical and practical guidance, along with examples from various global contexts.

Parry, D., J. Salsberg, and A. C. Macaulay. 2009. *A Guide to Researcher and Knowledge-User Collaboration in Health Research*. Ottawa: Canadian Institutes of Health Research (CIHR). http://www.cihr-irsc.gc.ca/e/44954.html.

These CIHR Knowledge Translation Learning Modules teach researchers the pragmatics of co-producing knowledge with those who must ultimately use the results of their research. The modules cover all areas of participatory research, including finding research partners, maintaining partnerships over time, overcoming barriers, co-designing research, and disseminating and navigating ethical considerations. Examples and cases are presented throughout.

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